

HCS HB 1387 -- NEWBORN SCREENING REQUIREMENTS

SPONSOR: Roeber

COMMITTEE ACTION: Voted "Do Pass with Amendments" by the Standing Committee on Health and Mental Health Policy by a vote of 11 to 0. Voted "Do Pass with HCS" by the Select Committee on Social Services by a vote of 9 to 0.

This bill requires the Department of Health and Senior Services, subject to appropriations, to add severe combined immunodeficiency (SCID), also known as the bubble boy disease to the list of newborn screening requirements.

The bill contains an emergency clause.

This bill is similar to HB 1315 (2015).

PROPOSERS: Supporters say that the bill expands newborn screening to include SCID, which is the absence of an immune system that causes infants to obtain recurrent, opportunistic infections. There is a 95% cure rate for SCID if it is treated right after birth, within one month, with stem cells before passive immunity received from the infant's mother wears off. Twenty-eight states currently test for SCID as part of their newborn screening programs. The Centers for Disease Control and Prevention (CDC) and the federal Department of Health and Human Services supports newborn screening for SCID. There is no cost to General Revenue in the fiscal note, but there is a cost to the Missouri Physical Health Fund. The addition of screening for SCID would increase the cost of newborn screening by \$7 to \$9 per child.

Testifying for the bill were Representative Roeber; Carrie Pathett; Mohamed Radhi; Missouri Department Of Health And Senior Services; Michelle Deatherage; Megan Wheeler; SSM Health Care; March Of Dimes Foundation, Missouri Chapter; Missouri Chapter Of American Academy Of Pediatrics; and Cathy Bozerocki.

OPPOSERS: There was no opposition voiced to the committee.

OTHERS: Others testifying on the bill say the purpose of newborn screening is early identification of illness where early intervention will change the outcome for the patient and that there actually is a treatment for intervention. Early identification is paramount to positive outcomes for patients diagnosed with SCID.

Testifying on the bill was St. Louis Children's Hospital.